

Sickle Cell Mutual Help Groups

*A Five Year Study: Information,
Findings, and Resources*



... African Americans
Supporting One Another

Psychosocial Research Division of the
Duke University/University of North Carolina
Comprehensive Sickle Cell Center

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This report covers a wide range of issues and a substantial amount of information. The contents are divided into five sections so that the reader may easily locate that information which is of interest.

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Starting or becoming a member of a mutual help group is a vital step toward empowering yourself and others. The Psychosocial Research Division hopes that this document is helpful in that endeavor.

Section One:

Overview of Mutual Help Groups

Overview of Mutual Help Groups

An **OVERVIEW OF MUTUAL HELP GROUPS** provides you with some brief information about why mutual help groups evolved, how they have grown, who joins a mutual help group, and what kinds of support these groups offer.

What is the Purpose of Mutual Help Groups?

Mutual help groups have developed from a human need for emotional support in times of stress and crisis. The traditional support provided by family, friends, and community life has greatly decreased in the past twenty years. Meanwhile, the pace of daily life has increased. New stresses -- economic, educational, environmental, political, and social -- have added to the feelings of isolation and helplessness large numbers of Americans are experiencing. Because there are no easy solutions, especially with problems or illnesses that are lifelong, many people are seeking and finding emotional support in groups dedicated to helping people help themselves (U.S. Department of Health and Human Services, 1987).

Evidence supports the belief that mutual help groups assist people in staying well, speed the recovery of those who are ill, and improve the quality of life in those for whom a full recovery is not possible (U.S. Department of Health and Human Services, 1987). Mutual help groups are vital care giving systems that allow interactions among individuals, providing them with opportunities to increase social support and knowledge.

The increase in the number of mutual help groups reflects their importance as an alternative means of care. It is estimated that half a million support groups are operating in the United States, providing a wide range of services for more than 10 million Americans (U.S. Department of Health and Human Services, 1987). Within the mutual help movement, the African American community has played an active and vital role. This is evident in the number of sickle cell mutual help groups located across the United States. Within these groups, members are finding support and learning how to cope with an inherited disease that primarily affects the African American community.

Who Joins a Mutual Help Group?

A mutual help group consists of a variety of people voluntarily coming together to discuss a common problem. Group members represent a number of distinct backgrounds, experiences, and lifestyles. If you asked what type of people join mutual help groups you would find that:

- Anyone (regardless of race, sex, religion, and ethnic background) who needs help in coping with problems can join a mutual help group.
- Both males and females can join mutual help groups.
- Adults as well as children of all ages attend mutual help groups.
- Anyone can join a mutual help group regardless of socioeconomic status.
- People from any occupation can join a mutual help support group.
- Friends and family members of people having difficulty in coping with problems can join mutual help groups.

Sickle cell disease does not affect just one person -- it affects the individual's entire support network. Thus, sickle cell mutual help groups offer support for a number of different people. Groups may include:

- People with sickle cell disease and the sickle cell trait
- Parents of children with sickle cell disease
- Grandparents, aunts, uncles, brothers, and sisters
- Spouses and partners
- Friends of people with sickle cell disease

What Kinds of Support Do Mutual Help Groups Offer People?

The activities of mutual help groups vary from group to group. Some groups focus on social activities, while others meet to discuss effective coping strategies for dealing with a problem or illness. The mutual help group also provides an excellent network for sharing pertinent information. Group members who have a great deal of experience in dealing with a problem or illness can be very helpful to those who are just encountering the problem. In addition, mutual help groups may invite speakers or professionals to group meetings to increase their knowledge about specific problems or illnesses. Other groups strive to combine all of the above activities in order to effectively meet the needs of group members.

And of course, one of the most valuable aspects of mutual help groups is the socialization that takes place. As individuals share information, experiences, and feelings, new friendships are often formed. These supportive relationships become a vital part of a person's support network, and these friendships may prove very helpful to those experiencing difficult periods in their lives.

Section Two:

Starting a Mutual Help Group

Conducting a Needs Assessment

The first step in starting a mutual help group is to identify the needs and interests of potential group members. This is often called a **NEEDS ASSESSMENT**. A needs assessment helps group organizers determine an organizational structure, a set of group beliefs, and a meeting arrangement that best serves group members. Two methods of conducting a needs assessment are interviews and questionnaires.

Interviews

Individuals often conduct interviews without even knowing it. An interview simply means talking to others to find out information. By talking with individuals, organizers of a group can more fully understand how potential group members feel about certain issues, and in the process, can bring together people who have common problems and goals.

For example, a mother of a newborn with sickle cell may wish to start a mutual help group. By talking to other mothers who have children with the disease, she may discover which issues are most important to them--such as guilt about transmitting a genetic disease, fear of the child dying, and difficulties negotiating a complex health care system.

Questionnaires

Questionnaires are written surveys that group organizers may use to elicit more specific information about potential members. Questionnaires may vary in length and in structure, from the simple to the very complex. Professionals are sometimes available to help group organizers develop a questionnaire specific to their needs.

For example, the mother in the previous example may decide to write a questionnaire to pass out at the sickle cell clinic asking if others would be interested in participating in a group, and if so, what they would like to see accomplished in the group.

Areas of Assessment

Several **AREAS OF ASSESSMENT** are critical to most mutual help groups during the early phases of formation. During the needs assessment process, group organizers should consider the following issues: group structure and group meeting arrangements.

Group Structure

When beginning a group, it is necessary to create an effective group structure which allows members both flexibility and support. Group structure includes: selection of leadership, the selection of formal vs. informal organization, and the delegation of responsibility.

- During a needs assessment phase, organizers should determine what type of leadership potential members feel most comfortable with.

*For example, groups are often first led by professionals such as social workers, psychologists, and doctors. Often, these leaders may give up their positions as the group evolves. Other forms of leadership may include having a lay person lead the group, or having the group be co-
led by both professionals and a group member.*

- Some groups choose to establish more formal structures which involve the selection of members to play specific roles (e.g., president, secretary, etc.). This is not to say that a more formal structure is needed to promote accomplishment, but it can be useful in relating to other community groups, organizations, and potential members.

For example, groups may elect officers, or establish a mission statement, constitution, and bylaws.

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- Traditionally, mutual help groups operate rather informally. Members often assume leadership roles in accordance with their interests and abilities, usually on a shared or rotating basis. This prevents one person from accepting too much responsibility, becoming overwhelmed, or dominating the group. Delegating leadership responsibilities may help to more effectively conduct a group. Also, in the case that an individual can no longer lead, the group will be able to continue.

For example, in a group, some members may share concerns about hospital administration problems and focus on those issues, while other members may wish to concentrate on the group's financial concerns and plan a fund-raiser.

Group Meeting Arrangements

Another outcome of the needs assessment process is gathering information from prospective members that will help establish meeting place, time, and length of meeting for your mutual help group.

- **Location** is a key factor to the success of your group. Potential sites should be easily accessible to participants.

The Division's study on sickle cell mutual help groups demonstrated that the farther the meeting site is from a group member's home, the greater the chance that the group member will not be able to attend regularly or will drop out of the group altogether.

- **Transportation** issues must also be considered. Staff or group members may want to develop a system to ensure that all group members have transportation to meetings and other group related activities. Group members should discuss and explore the following issues: who has a car; who lives in the same area; who has access to public transportation; can organizations such as the Red Cross and local churches provide help with transportation; and can fundraising help with transportation costs for some members?

For example, group members who do not have cars or access to public transportation may consider carpooling with other members or staff that have cars.

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- **Time** of meetings should be worked out between group leaders, members, and professionals. Determine what time frame will maximize attendance.

For example, organizers should try to schedule meeting times around jobs, school, family life, and other responsibilities.

- **Frequency** of meetings is also an issue. Group members should decide when to meet, how long, and how often the meetings should take place.

For example, some groups choose to meet once a week for an hour, while others choose to meet once a month for two hours. Once again, group members and leaders should come to a consensus on this issue.

- **Child care** may also be critical for some members who have children.

Oftentimes, groups conduct a "mini-daycare" at the meeting location. Children can play in another room while members meet. Friends, family members, or older children can volunteer to watch the smaller ones during the meeting.

Recruitment of Members

RECRUITMENT OF MEMBERS is an important aspect of mutual help groups. There may be many individuals who would like to discuss a common problem and share experiences, but the question is, how do group organizers contact these people? Some activities that have proven successful for new groups are: passing of information by word of mouth, or at clinic visits, church and other community presentation;, distribution of group information; and directory listings.

Getting the Word Out About Your Group

One of the most effective ways of passing on information is by word of mouth. By telling friends, relatives, co-workers, church members, and hospital workers of their participation in a mutual help group, individuals can relate information about their group to a great number of people.

For example, leaders or members can visit hospital clinics and talk to doctors, nurses, and patients about their group. They may also wish to present information to people at church gatherings and community events. Information can be spread by word of mouth at beauty shops, coffee shops, and other small businesses. Members of sickle cell mutual help groups may wish to call local and/or national associations which serve individuals with sickle cell disease and tell them about the group.

Another way to attract individuals to the group is to distribute information about the needs and goals of your group. This not only educates people about your group's common concerns, but it also publicizes your group's existence. However, relating information both by word of mouth and by written materials may be the best way to reach the largest number of individuals.

For example, brochures, newsletters, newspaper articles, and reader's announcements are basic modes of communication. They should serve as links between members and outside organizations, and should be forums for ideas, demonstrate activities in which members can participate, and give credit for accomplishment.

Directory Listings

One way to ensure that potential members discover your group is through the directory listings of various associated organizations. If your group is interested in making referrals or advertising for potential members, there are many national directories to choose from. One example is *The National Sickle Cell Mutual Help Directory*. This directory is compiled by The Psychosocial Research Division at the University of North Carolina at Chapel Hill. If your group would like to be listed in this directory call (919) 966-5932 or write to:

The Psychosocial Research Division
University of North Carolina
CB #3560, 309 Battle Hall
Chapel Hill, NC 27599-3560

Other directories provide different information and resources. For example, *Help!: A Guide to Sickle Cell Disease Programs and Services* contains names and addresses of sickle cell centers and associations offering education about sickle cell disease, tests, counseling, and referrals. Please call 1-800-421-8453 or write to the following address for more information about this directory:

National Association for Sickle Cell Disease, Inc.
3345 Wilshire Boulevard, Suite 1106
Los Angeles, CA 90010-1880

Letting various sickle cell centers, public health clinics, mobile health clinics serving shelters, programs for single teen mothers, and group homes know of your existence will help ensure that potential members discover your group.

Development of Group Beliefs

In order for a group to function smoothly, it should have a clearly established system of beliefs to guide its actions and evolution. The goals of the group will be determined by the **GROUP BELIEFS**.

Group beliefs are the beliefs and goals held by group members, justifying and supporting their proposed action or existence.

For example, a mutual help group for parents of children with sickle cell disease may believe that parents should encourage their children to achieve and to work toward goals, instead of imposing restrictions and limitations on them. This belief will guide the group's discussion and actions concerning child rearing, education, and societal expectations of chronically ill children.

- Groups should decide on and develop a belief system. For example, this belief system may be one of empowerment, better modes of coping, social and political change, etc.
- Group members should also think about attainable goals and objectives, and decide what it is they hope to obtain from participating in a mutual help organization. In addition, groups should always keep their goals and group ideology in mind during meetings to ensure success and productivity.

Section Three:

Conducting a Successful Group



Meeting Members' Needs

In order to conduct a successful mutual help group, leaders must concentrate on **MEETING MEMBERS' NEEDS**.

Voluntary organizations frequently have difficulty sustaining membership and activities. In order to retain membership, leaders should focus on the ongoing evaluation of group needs the implementation of group goals, and the organization of social activities.

Ongoing Evaluation of Members' Needs

Needs assessment is an on going process which continues even after your group has started. Thomas Wolf wrote in his book, The Nonprofit Organization (1984) that "...a non-profit organization must identify clearly those it intends to serve, and once it does so it must work toward organization structure -- through boards, staff and activities -- which strengthens its commitment to that group" (p. 15). As groups move through different stages, group leaders need to evaluate their members' changing needs.

For example, in the early phases of a sickle cell mutual help group, members may need to express their feelings about having sickle cell disease, but as the group evolves, members may become more interested in advocating for changes in the health care delivery system. Group leaders must recognize these changing needs and be willing to accommodate them.

Groups are made of many individuals who have distinct and varied needs. Some members may find that the group is able to meet their needs by scheduling meetings at convenient times or discussing issues that are of relevance to them; however, other members may find that the group is not able to meet their needs as well or as quickly. Group leaders must work to provide a comfortable atmosphere in which each member can freely express his or her opinions and feelings about the group meeting arrangements and activities.

For example, leaders can schedule a certain amount of time during each meeting to ask how members feel about such issues as meeting length and time and current group activities. This can be done verbally or in writing. Everyone in the group should be given a chance to contribute to the discussion.

Implementation of Group Goals

Although groups may clearly establish goals, they often have difficulties in implementing them. In the early stages of formation, mutual help groups should ensure that each individual group member takes initiative in implementing group goals. Essentially, no group member should assume that someone else will take responsibility for doing all the group work. Clear discussion and delegation of roles will ensure effective group functioning. This can also help prevent loss of interest by leaders who often accept a greater share of the responsibility than can be handled. It is important to involve as many members as possible in the organization to maintain commitment and share responsibility.

Social Activities

Another way to help members feel more comfortable with the group is to organize social events. Many group members join primarily for the new friends and activities they share in mutual help groups. During meetings, groups can offer refreshments or have members bring in small dishes. Sharing food and conversation helps people to enjoy the social aspects of mutual help groups.

Many groups reported that they raised funds to support some social activities. Fundraising efforts can include bake sales, car washes, and raffles. Most of these fundraisers are organized by members of the groups. If you seek other funds for group events, you may try to call local organizations (i.e., local community chest) or call mutual help clearinghouses to ask if they have heard of any other organizations who might fund some of the activities of your group.

Group Communication

COMMUNICATION is important in any relationship, and it is certainly crucial to the success of a mutual help group. Since the purpose of a group is to share feelings, knowledge, and experiences with others, communication between group members and between members and leadership is vital. When participating in a group, individuals should listen, recognize individual differences, and promote giving and receiving.

Listening

Listening is the key to effective communication. How do you let someone know you are truly listening to him or her?

- *Pay attention!*
- *Do not interrupt!*
- *Use eye contact!*
- *Give feedback!*
- *Share your thoughts and feelings!*

Recognition of Differences Among Group Members

Each person brings his/her own feelings, thoughts, beliefs, and experiences to a communication exchange. What is being said is processed through personal filters. Hence, it is important to check out the other person's meaning with him or her (Mental Health Association of Houston and Harris County, Inc., 1991). Group leaders and members should recognize that these differences exist, and be sensitive to them. This will help to alleviate some of the miscommunication that causes individuals to feel alienated.

Promotion of Help-Giving and Help-Receiving Among Members

An important feature of groups is the "giving and receiving" process which occurs between members. Individuals learn from one another; more specifically, they learn from other's experiences. In a mutual help group, this giving and receiving process may produce changes in an individual's coping strategies, modes of thinking, and perceptions.

For example, a new member of a sickle cell mutual help group who is having a hard time dealing with a "crisis" or the severe pain that goes along with it, may learn from a more experienced group member how to manage better and cope with the pain.

Criteria for Effective Group Leaders

The success of a group depends also on the overall **EFFECTIVENESS OF ITS LEADER**. Group leaders should continually try to evaluate their role and their effectiveness. The following criteria may be helpful.

- The person must want to be a helper.
- The person must be able to talk easily about his or her own experiences. He or she must be able to share both successes and failures with the group.
- The leader must have sensitivity to the problem (e.g., sickle cell disease).
- The support offered may best be derived from personal experiences rather than prior education or training.
- The leader must allot enough time to take on responsibilities and give needed attention to group concerns.
- The leader must be empathetic, able to listen, and able to learn from the person(s) being helped.
- Groups are dynamic -- leaders need to value and understand the nature of personal change.
- Leaders must value people's feelings and understand the concept of emotions. Group leaders must recognize that different people express emotions in different ways, and these support groups should serve as a forum to allow group members to ventilate their emotions freely.
- Leaders must be willing to phase themselves out over time and become a resource person, allowing leadership to arise from within the group. Groups can help this process by giving individual members specific tasks or responsibilities that will help them develop their own skills. Also, having co-leaders for different activities allows individuals to discover their own leadership skills.
- Leaders must constantly monitor group needs -- adjust group, content of meetings, leadership roles -- as membership needs change and dictate.

Making Your Group an Effective Tool for Change

Many people join sickle cell mutual support groups in order to **MAKE CHANGES** in health policies. Your group can be more effective at this by making its presence widely known, at the personal level and at the community level.

Making Changes in Health Policy

The Psychosocial Research Division has learned that one of the reasons people join sickle cell support groups is to make changes in the health care delivery system. Since there is strength in numbers, support groups are in a unique position to make these changes, but they are often frustrated in their efforts. Your group is important; however, there are many people in the health care community who do not know about your group or about the benefits group members receive. Also, some health professionals think that support groups are anti-professional and may resist your efforts unless they are shown otherwise.

One-to-One Communication

A study recently showed that many doctors are unaware that their patients attend support groups (Fridinger, Goodwin & Chng, 1992). Doctors reported that they would refer more patients to support groups if they knew about their existence. The more doctors hear about support groups, the more likely they will listen to their suggestions. They may even help you in your membership drives by referring patients to your group! Encourage group members to:

- Make a point of telling their doctors, nurses, and social workers about their involvement in a support group. Having members practice what they will say helps them to overcome any anxiety they may feel when speaking to professionals.
- Emphasize the benefits received from being in the group, especially learning how to deal with emergencies, how to cope with depression and/or pain, compliance with treatment, and living healthier lifestyles.

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- Be friendly and non-combative -- show doctors, nurses, and social workers that support groups are not anti-professional. Mutual support groups do not strive to take the place of professional services, but to augment them.
 - Explain that they joined the group voluntarily and that there are many other groups like it around the country. Many people are still unaware about the extent to which African Americans are organized.

Community Level Activism

Efforts can also be made by the group as a whole to advertise the existence of the group. Increased awareness and change at the community level will require group effort.

- Create written materials about your group and the benefits members receive which you can hand out to people in the hospital, at meetings, or by mail. These don't have to be long -- in fact, the briefer, the better -- but keep them up-to-date.
- Make presentations about sickle cell disease and your group at local hospital staff meetings, in nursing and medical schools, or in places where health care providers are in continuing education classes. Emphasize the psychosocial impact of the disease.
- Send letters and materials about your group and its benefits to the editors of local publications, church publications, and professional health care journals.
- Utilize the genetic disease and support group clearinghouses to make information available to those who request it.
- Collaborate with other types of support groups in your efforts to educate the community about sickle cell disease and about your group.

Section Four:
Study Findings

STUDY DESCRIPTION

During the last five years, the Psychosocial Research Division has conducted a series of studies on mutual help groups for persons affected by sickle cell disease. Section Four is divided into the following five components: Study Description; Group Information; Individual Information; Adolescent Information; and Factors Affecting Groups and Long Term Success.

The Psychosocial Research Division is a component of the Duke University/University of North Carolina Comprehensive Sickle Cell Center, one of the ten federally funded Comprehensive Sickle Cell Centers in the United States. In the fall of 1988, the Division received funding from the National Heart, Lung, and Blood Institute of the National Institutes of Health to conduct a five year study on Sickle Cell Disease Mutual Help Groups. Using personal contacts, telephone interviews and mail survey techniques, the Division spent the first year of the study locating mutual assistance groups throughout the United States. Originally, 429 individuals or organizations were contacted (e.g., National Comprehensive Sickle Cell Centers, Sickle Cell Clinics, Sickle Cell Associations and Foundations, State Health Departments, and State Genetic Counselors). By 1989, 74 groups were located in the United States. Currently, the number of groups known to the Division has almost doubled. The 1992 National Sickle Cell Mutual Help Directory contains information on 134 groups. Learning about the existence of these groups was just the first step in understanding the mutual help group process.

Tracking Sickle Cell Mutual Help Groups

Since 1988, the Division has conducted yearly surveys to locate new groups and update information on groups already known. To enhance the tracking process and to provide information to the community, three directories of sickle cell mutual help groups have been published and distributed by the Psychosocial Research Division. The directories list the location of each group and the group's contact person, address, and phone number. Through networking efforts, the Division is able to update group status yearly and locate new groups continuously. An understanding of the dynamic process of mutual help groups has resulted from these efforts. More and more, it has become clear that groups are always changing -- groups form, leadership rises from within the group and changes frequently, members join and leave, and groups end. The information gathered from tracking groups provides insights into the birth and death rate of sickle cell mutual help groups, and coupled with information from other studies, provides clues about factors which promote or hinder the long term success of mutual help groups.

Descriptive Studies of Sickle Cell Mutual Help Groups

In addition to tracking groups, the Division has conducted a series of descriptive studies on sickle cell mutual help groups over the past three years. Beginning in 1989, two different kinds of information were collected from sickle cell mutual help groups: group information and individual information. Group information was provided by group leaders who answered questionnaires focusing on such characteristics as group location, group leadership, number of members served, and group functioning. Individual members provided the second type of data by answering questions about their gender, age, education and income level, and about their personal experiences with the group. Over the years, the Division has collected data for:

- Adults with sickle cell disease
- Parents of children with sickle cell disease
- Adolescents with sickle cell disease
- Any persons affected by sickle cell disease

The Division has also learned about some of the newest groups that are forming throughout the United States, including groups for parents of newborns with sickle cell disease and peer support programs.

The information in Section Four presents an overview of some of the preliminary findings from our studies. Information for this report has been derived from three different time periods or data collections. The latest data collection was completed in June 1992 and provides information about the location and type (adult, parent, mixed, and adolescent) of 134 groups in the United States and Canada. An earlier data collection was conducted from 1990-1991, and provides more in-depth information on both a group and an individual level for three types of groups: adult, parent, and mixed (serving anyone affected by sickle cell disease). The adolescent information provided by teenagers with sickle cell disease who are members of mutual help groups was collected in a study recently completed by the Division.

It must be stressed that this report provides preliminary finding from studies and data analysis will continue throughout the year. In the future, the Division will continue a program of research in this area that will rigorously test some of the findings noted during the first phase of research.

Group Information

GROUP INFORMATION reported here is derived from two different data collections. The latest data collection from 134 groups, completed in June 1992, provides information about group location and group types. The data from 1990-1991 represents 52 groups from 27 states and provides information about general group characteristics such as length of group existence, number of members, and leadership characteristics, and about group activities and special features of groups.

GROUP INFORMATION 1992

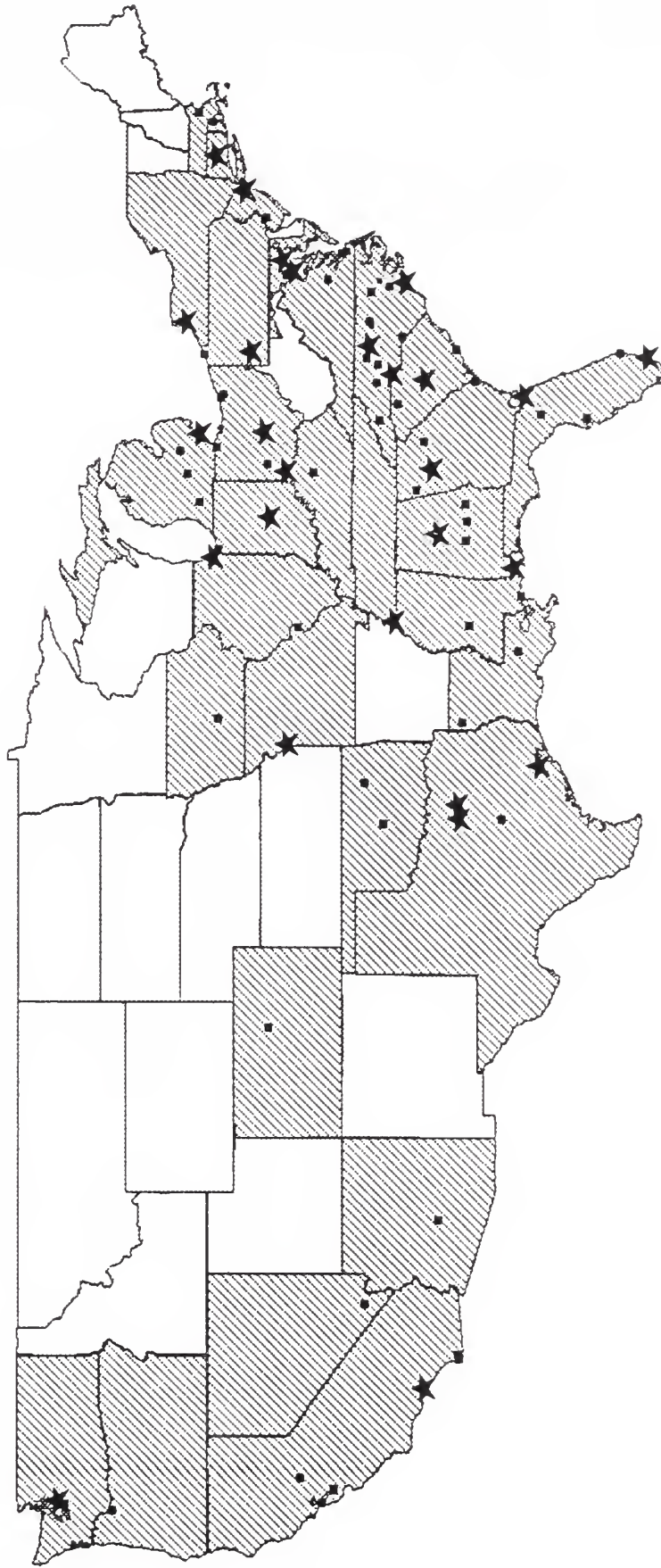
Group Location

By the end of June 1992, the Psychosocial Research Division had contacted 168 groups. Of those groups, 53 were newly discovered groups and 26 had disbanded or were defunct. At the time of the survey, 134 groups were actively meeting in 31 states, the District of Columbia, and one province of Canada (see map, page 33).

Group Types

There are many different kinds of sickle cell mutual help groups in the United States, serving a variety of people. Of the 134 groups, the majority (47 %) of the sickle cell disease mutual help groups observed were classified as mixed groups. Mixed groups serve *any* person affected by sickle cell disease including children, family, and friends. Parent groups made up the second largest category (22 %). These groups serve parents of children with sickle cell disease. The other groups found were adult and adolescent groups. Adult groups made up 16 % of groups and focus primarily on adults with sickle cell disease. The adolescent groups represented 15 % of the 134 groups serving ages 12 to 21 (see chart, page 35).

Sickle Cell Mutual Help Groups

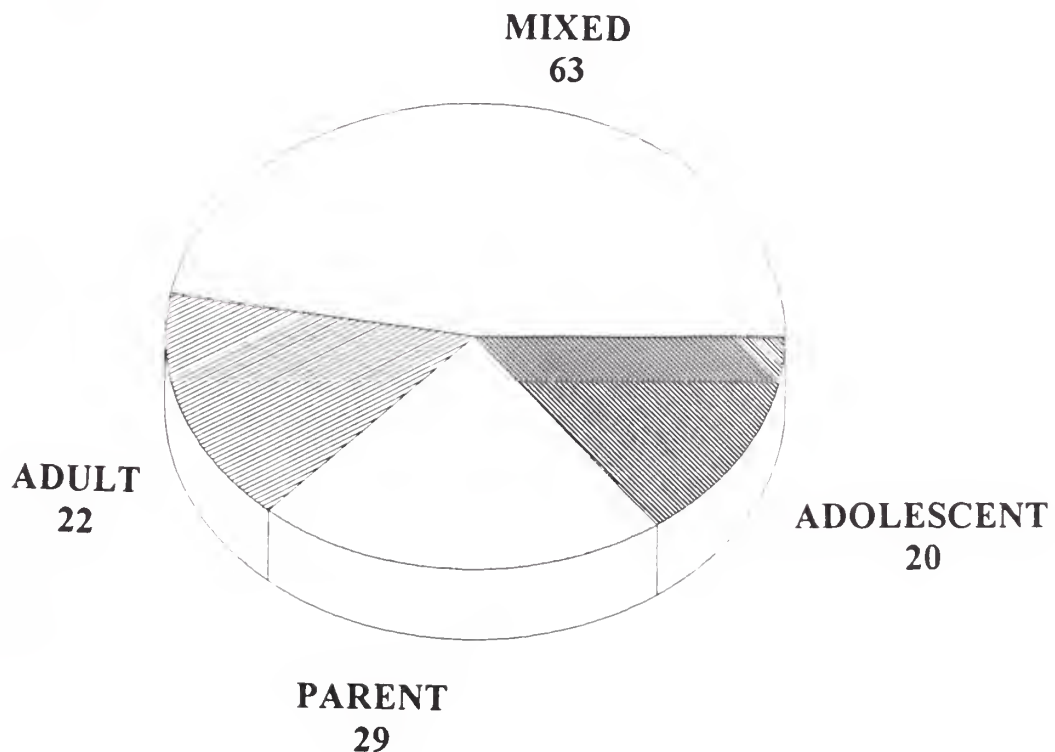


134 groups in 31 states and
Washington, D.C. (and Canada)

August 1992

MUTUAL ASSISTANCE GROUPS

(Number of groups by focus of group)



Total number of groups: 134
(July, 1992)

Since the Division began collecting group information in 1988, staff have noticed that groups are becoming more specialized according to member needs. The Division previously noted that most groups were mixed or open to all who were affected by sickle cell disease. The latest survey of sickle cell mutual help groups demonstrated an increase in more specialized groups, such as adolescent mutual help groups and groups for parents of newborns with sickle cell disease.

GROUP INFORMATION 1990-1991

Average Age of Group

Sickle cell mutual help groups in the study had existed for an average of 6 years. The adult and mixed groups had existed the longest, 6 years and 7.5 years respectively, while the average age of parent groups was 4.5 years.

Gender of Group Members

Across all groups, more women than men joined sickle cell mutual help groups. For every 5 females, 2 males participated in sickle cell mutual help groups. However, there was great variability according to each group type. In adult groups the ratio was 1 woman to 1 man, in mixed groups 2 to 1, and in parent groups 4 to 1.

Numbers of Regular Attenders

Across all groups, the average number of members attending a mutual help group was 9. In adult groups, the average number of members was 6; in mixed groups, 15; and in parent groups, 9. Thus, groups are relatively small, ranging from 6-15 members. The small group size, however, is optimal and recommended by experts on group interventions. If you have groups larger than 15, you may want to split into 2 groups.

Group Leadership

Over 90% of all groups were started by a professional (e.g., social workers, psychologists, or nurses). However, at the time of the survey, group leadership had changed for several groups -- 46% of groups had a member as leader, 25% had a professional leader, 17% had no leader, and 12% had co-leaders.

Overall, 76% of group leaders were female and the average age of the leader was 41 years old. In terms of education, 44% of leaders had 17 or more years of education, and 32% had college experience. Only 4% had the equivalent of or less than a high school education. A majority (81%) had incomes of \$25,000 or more. Thus, the leaders tended to be highly educated and well-trained individuals.

Group Activities

From a list of possibilities, group leaders were asked to select the activities in which their group engages. The most frequently selected activities were:

- *Discussing* personal feelings and emotional issues
- *Helping* one another
- *Learning* about sickle cell disease
- *Advocating* for changes in hospitals, clinics, and emergency rooms
- *Conducting* social events

It is important to note that these are merely some of the activities that many groups find helpful. Some of these activities may or may not work for your group. Leaders should evaluate their members' needs to determine which activities may be most appropriate for their group.

Special Features of Groups

Group leaders were asked to identify the special features that were associated with their groups' activities. More than half of all the groups in the study reported engaging in the following special features:

- *Visiting members* while they were hospitalized
- *Visiting members* at their home during respite care
- *Providing transportation* for other members to group meetings
- *Providing speakers* for other groups
- *Raising funds* for needy members
- Establishing a *buddy system* for group members

Individual Information

In a data collection from 1990-1991, members of groups also provided **INDIVIDUAL INFORMATION** about their education, income, and employment, as well as reasons for attending group meetings, information about member participation, and benefits from participation. The information below represents findings from 152 individuals from 29 groups across the United States.

INDIVIDUAL INFORMATION 1991

Education of Group Members

Members of sickle cell mutual help groups come from all educational backgrounds. However, study findings showed the average number of years of education across all group members was 13. Half of all members (50%) had a high school education or less. Meanwhile, 29% of group members had technical or college experience.

Income of Group Members

The income of group members varied. Over 50% of sickle cell mutual help group members had incomes of \$15,000 or less. Thirty-one percent had incomes between \$25,000 and \$45,000.

Employment of Group Members

Many members of sickle cell mutual help groups classified themselves as disabled, and this necessarily affected employment status. The data showed that 41% of adults with SCD were employed, while 31% were disabled.

Reasons for Attending Meetings

Participants indicated a variety of reasons for attending group meetings. More than 60 percent of all participants indicated that they attended:

- to *give support* to other group members (approximately 82%)
- to *learn* more about sickle cell disease (approximately 78%)
- to *improve* their health care (approximately 77%)
- to *get support* from other group members (approximately 61%)

Other reasons for participation included:

- to *raise money* for causes
- to *make new friends*
- to learn more about how to *solve personal problems*
- to have a *safe place to express feelings*
- *to have social activities*
- and to have a *sense of belonging* to a group

Member Participation

Over 70% of group members in this study lived within 10 miles of the meeting site. Most group members either drove themselves to group meetings or car pooled. Less than 10% of group members used public transportation or walked to the meetings.

Many of the groups which participated in this study reported that it is common for their members to be active in other organizations as well (68.9%). The number of other organizations (including churches and civic groups) in which members participated ranged from 1 to 6.

In addition to seeking help from the mutual assistance groups, other help seeking behaviors were reported among the sample. Participants (24.6 %) also sought help from the clergy and from psychotherapists (i.e., psychiatrists, psychologists, and social workers) (24.6 %).

Benefits of Group Participation

Members who had attended a mutual help group for an extended period of time reported that they received several benefits from participation. Some of the psychosocial benefits members reported were:

- *Obtaining information* regarding SCD
- *Meeting others* with similar problems
- *Feeling free* to express feelings
- *Coping* with attitudes toward the condition of SCD
- *Expressing* and/or *learning* compassion
- Developing *self-confidence*

Adolescent Information

During 1991-1992, the Psychosocial Research Division began collecting information on **ADOLESCENT MUTUAL HELP GROUPS**. As of July 1992, 20 groups had been located in the United States and Canada. Of those 20 groups, 10 groups provided in depth data on their members and activities.

GROUP INFORMATION 1992

The average age of the adolescent groups was 3 years. Some of these groups were restarted after several years of not meeting (e.g., one group was started twenty-five years ago and has met off and on since then). There were as many male as female members. The typical number of members who attended group meetings was 10.

Group Leadership

Almost all of the sickle cell adolescent mutual help groups were started and led by professionals. More than half of the group leaders were married (60 %). Most had at least a graduate school education (70 %); about half were social workers (50 %). All leaders were involved with mutual help groups due to their profession (100 %). About half had incomes of \$45,000 or more (50 %); none had sickle cell disease; most were African American (90 %); and all were female (100 %).

Group Activities

More than 80 percent of the sickle cell adolescent mutual support group leaders reported that their members participated in a number of activities as a group. The following are some of these activities:

- Talk about things which cause stress on the family
- Talk about very personal feelings
- Talk about advances in treatment
- Learn to deal with emotional issues
- Practice dealing with certain situations
- Give advice to one another
- Listen to experts talk about sickle cell disease
- Talk about school issues
- Talk about friend or companion issues
- Talk about what it is like to live with sickle cell disease
- Talk about relationships with parents and family

Please note that these activities were asked of the group leaders. There may be many other activities that groups can and want to do. Group leaders should continually talk to their groups in order to plan and carry-out activities that meet the needs of the group members. One recommendation that can be made to adolescent groups and their leaders is the implementation of youth leadership training. Since the principal objective of a mutual help group is empowerment of its members, training for adolescents can help them with leadership skills development. This will help them gain some control in what is often a difficult period of their lives.

Special Features of Groups

Adolescent group leaders were asked to identify any special activities as a support feature of their group. At least half of all the groups reported engaging in the following special activities:

- *Visit members* while they were in the hospital (80 %)
- Have a *buddy system* (50 %)
- *Provide transportation* to meetings (60 %)

INDIVIDUAL INFORMATION 1992

Reasons for Attending Group Meetings

Sickle Cell Adolescent mutual support group members listed a number of reasons why they attended meetings. More than half stated that they attended meetings:

- To *learn* more about sickle cell disease (90.8 %)
- To *get support* from others (60 %)
- To *give support* to others (63.1 %)
- To *have social activities* (50.8 %)
- To help *improve the health care* for people with sickle cell disease (70.8 %)
- To *make new friends* (70.8 %).

Individual Experiences

More than 65% of those adolescents in the study lived 10 miles or less (66.2 %) from their meeting place. Most were transported to the meetings by family members (49.2 %). About 40 % took public transportation to get to the meeting.

More than half (52.3%) of the adolescent group members in the study started attending the group in the spring months (March, April and May) (52.3 %) of 1991 and 1992 (63.1%). Most attended the meetings about every time they occur (63.1 %). Many members were also active in other groups (55.6 %) (i.e., sports and church groups).

Many adolescent group members felt that they both give and receive the same amount of help as other participants in the groups (46.9 %). In addition to getting help from the groups, more than half of the adolescents in the study reported that they receive help from family and friends (55.4 %). In addition, a social worker was the most cited professional (33.8%) from whom members sought help in time of need.

Benefits of Group Participation

Sickle cell adolescent mutual support group members reported a number of benefits or kinds of help they received via their participation in these groups. The following is a list of the kinds of help at least 80% of those adolescents in the study reported that they received via their participation:

- *Getting information* about SCD
- *Getting practical advice* from others
- *Being helpful* to others and *feeling supported* by others
- *Learning to deal with family problems*
- *Learning to cope differently, dealing with attitudes*
about sickle cell disease, and living with sickle cell disease
- *Learning their rights* as individuals
- Helping to *develop self-confidence*
- Feeling free to *express their feelings*

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- *Meeting others* with similar problems
 - *Expressing and learning compassion* or care for others
 - *Becoming more hopeful*
 - *Having more fun*
 - *Dealing with problems at school*

Groups can serve a vital resource in meeting the needs of their members. Our findings indicate that when group leaders and members take advantage of these opportunities they are able to get the most out of their group involvement.

Factors Affecting Groups and Long Term Success

In addition to its study on mutual assistance groups serving African Americans, the Division of Psychosocial Research has conducted a study on the **FACTORS WHICH HINDER OR PROMOTE** the formation, growth, and development of SCD mutual help groups.

Professional Involvement in Groups

The study on factors which hinder or promote group formation suggested that successful groups are likely to emerge when professionals assist in the formation of groups or contribute to group leadership without assuming total control. Most of the professionals across the groups tended to be social workers, nurses, psychologists, or others from health care professions. Professionals can be effective in organizing and facilitating the formation of mutual help groups because of their knowledge of group development, dynamics, and goal attainment.

In addition, research supports that groups appear to thrive when professionals assist in the initial formation of groups and gradually move into an indirect, non-authoritarian role as consultant to group members.

The challenge for professionals and members is to know how and when to modify their roles. This is critical because achieving that delicate balance between under and over-involvement of professionals may be the key predictor of long-term group success or failure.

Factors Which Hinder Group Formation and Development

All groups encounter obstacles as part of organizational and growth processes. Some of the common barriers cited by the sickle cell mutual help groups in the study are as follows:

- *Illness or death* of members or leaders
- *Lack of direction* within the group
- *Irregular attendance* of group members
- *Distance to meetings* is too far
- *Dominating and controlling* members
- *Dominating and controlling* leaders
- *Time constraints* of group members
- *Conflicting agendas and priorities*

Factors Which Promote Group Success

Although it is expected that all groups will encounter problems, there is no need to let these problems overwhelm you. Here are some key factors that may help promote success in mutual help groups. Several groups in the study reported the following as important contributing factors to effective group functioning:

- *Development* of a common goal
 - *Member commitment* to group goal attainment
 - *Mutual concern and support* among all members
 - A *committed* group with the ability and willingness to *motivate* other members to attend and participate in the group
 - An abundance of *social activities* and/or *group projects*
 - *Prayer and religious faith*
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Conclusions

Throughout the United States, African Americans are participating in mutual aid processes. In particular, African Americans affected by sickle cell disease are seeking and finding support through mutual help groups. These groups do not take the place of professional services or traditional forms of support (i.e., the family, church, and community); rather, they augment them. In an age when systems such as the health care network and the family network are greatly stressed due to social and economic conditions, sickle cell mutual help groups provide a strong source of support for individuals with sickle cell disease, and their family and friends.

Any individual who wishes to start a mutual help group or to enhance one which already exists should consider several issues. Organizers and/or leaders should constantly evaluate the needs and goals of the group's members. This is a continual process and involves consideration of different factors at different phases of the group's development. When starting a mutual help group, organizers should consider factors such as location, time, and length of group meetings and should focus on development of a belief system to guide group actions and discussion. When striving to conduct a successful group, leaders should focus on developing opportunities for the members to assume the leadership role. The membership should develop a goal and needs calendar that provides specific targets that can be measured monthly. In this way members learn the process of evaluation in a practical manner. Communication between members and between leaders and members becomes crucial for group success. Other factors such as fund raising and publicity about the group's existence and goals may contribute to its effectiveness.

In addition, findings suggest that professional involvement at the beginning phases of group formation is advisable. However, involvement should be phased out over time and leadership of group turned over to group members. The principal objective of a mutual help group is the empowerment of its members. By assuming various tasks and roles, members develop their own leadership skills and learn valuable techniques that will help them in their daily lives.

Information about the location and type of sickle cell mutual help groups across the United States and Canada was collected in June 1992. One hundred thirty four groups participated in this data collection. The information provided will be published in the *National Sickle Cell Mutual Help Directory* and distributed in the fall of 1992. Of these groups, 63 were mixed; 29 were parent; 22 were adult; and 20 were adolescent. Additional in-depth group level and individual level information was derived from a 1990-1991 data collection. The data revealed much variety among group members. There was no set income, educational level, or employment type for sickle cell mutual help group members. Group leaders tended to be more affluent and to have received more formal education than group members.

In addition, most people live within 10 miles of the meeting site. Thus, recruitment may be most difficult in rural areas where clients live over a large geographic area. In cases such as these, other formats for providing support may be most helpful (i.e., peer support programs, phone contacts).

Preliminary findings also suggest that participation in a mutual help group may offer a number of psychosocial benefits. Group members who had been active in the group the longest tended to benefit more psychologically from the group experience. Some groups had members that have attended for as long as 21 years. When the relationship among length of membership (as a measure of involvement in group) and outcomes associated with participation was explored, it was shown that long term members reported: 1) fewer psychosocial interferences in daily living (e.g., in work/school, leisure activities, daily tasks) and 2) fewer psychological symptoms (i.e., depression and anxiety). Thus, some people do appear to benefit from group participation. However, additional and more rigorous research is needed in this area.

It should be acknowledged that the Division does not view mutual help groups as a panacea for all. Findings show that 69% of group members are active participants in other group (i.e., church groups, community service groups, etc.). Thus, a majority of the members of mutual help groups are individuals who appear to function well in the group format. Some individuals, however, may best be suited for individual intervention.

It is hoped that the information provided in this report will contribute to the awareness of the existence and of the benefits of mutual aid groups among African Americans in the United States.

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Section Five:
References and Resources

References and Resources

This final section is a list of **REFERENCES** and **RESOURCES**. It has been included to help those of you who are interested in starting groups or enhancing groups that are already in existence.

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